



September 2022

**Shadow Report submission: Australia**

**By Intersex Human Rights Australia (IHRA)**



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## 2 Introduction

Thank you for the opportunity to put a shadow report to the Committee against Torture ('the Committee') regarding the ill-treatment of people with intersex variations in Australia.

A pattern of human rights abuses on infants, children and adolescents with intersex traits persists in Australia, including those that Juan E. Méndez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, has described as:

*irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, 'in an attempt to fix their sex', leaving them with permanent, irreversible infertility and causing severe mental suffering (UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment 2013).*

These abuses are often the product of stigma, and they provoke shame and suffering. They can occur with public funding and governmental imprimatur, despite rhetoric by Australian governments that asserts the equality and dignity of LGBTI (lesbian, gay, bisexual, transgender, intersex) people, and recognition and valuing of people with intersex variations, and despite opposition by intersex community organisations, human rights institutions, and mental health professional organisations (Carpenter 2022).

In this report we outline international obligations, as advised by UN Treaty Bodies, key national report and position statements, and evidence of human rights abuses in medical settings. We also summarise some of the legislation that facilitates such violations.

### 2.1 About this submission

Intersex Human Rights Australia (IHRA) is a national charitable organisation run by and for people with innate variations of sex characteristics. We were formerly known as Organisation Intersex International Australia and made a submission to the Committee under this name in July 2016.

We registered as a not-for-profit company in 2010 and became a charity in 2012. Since December 2016 we have been funded by foreign philanthropy to employ two part-time staff to engage in policy development and systemic advocacy work.

We promote the health and human rights of people with innate variations of sex characteristics, including rights to bodily autonomy and self-determination. Our goals are to help create a society where intersex bodies are not stigmatised, and where our rights as people are recognised. We build community, evidence, capacity, and provide education and information resources. Our staff and directors engage in work promoting consistent legislative and regulatory reform, reform to clinical practices, improvements to data collection and research. We also work to grow the intersex movement and the available pool of advocates and peer support workers, and address stigma, misconceptions and discrimination.

Our work is conducted in line with a 2017 community-designed platform, the *Darlington Statement*, which sets out priorities for the intersex movement in our region (AIS Support Group Australia et al. 2017). Together with Intersex Peer Support Australia (IPSA, also known as the AIS Support Group Australia) we comprise the Darlington Consortium.

## 2.2 Authorship

This submission has been written by Morgan Carpenter, M.Bioeth (Sydney), M.InfTech (UTS), executive director of IHRA. It has been supported through review and feedback by our board of directors.

Morgan Carpenter is a graduate in bioethics at the University of Sydney School of Medicine. He wrote our submissions to Senate inquiries on anti-discrimination legislation, and involuntary or coerced sterilisation, and also participated in hearings on those inquiries. He participated in the first intersex expert meeting, organised by the UN (Office of the High Commissioner for Human Rights 2019). He was an expert and drafting committee member for the *Yogyakarta Principles plus 10* (Yogyakarta Principles 2017) and a member of an Australian Human Rights Commission expert group on protecting the human rights of people born with variations of sex characteristics in the context of medical interventions (Australian Human Rights Commission 2021). Carpenter has consulted or been a reference group member for the UN Office of the High Commissioner for Human Rights, the World Health Organization, the ACT government, Australian Bureau of Statistics, NSW Health, and other bodies. His doctorate studies in bioethics at the University of Sydney School of Public Health focus on epistemic injustice, medicine, law and the human rights of people with innate variations of sex characteristics.

Some information in this report is drawn from a 2021 report by Morgan Carpenter written to inform the Australian Institute of Health and Welfare (Carpenter 2022).

### **3 Recommendations**

In line with previous recommendations by UN Treaty Bodies, and recognising a failure of Australian governments to address these issues, we respectfully request that the Committee recommend to the Australian government that it:

- Adopt clear national (or nationally consistent) legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on children with innate variations of sex characteristics before they reach the legal age of consent, consistent with the intent and approach expressed in draft legislation developed by the Australian Capital Territory
- Implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilisation of intersex persons, and the recommendations made by the Australian Human Rights Commission in 2021
- Provide adequate resourcing for independent counselling, support and advocacy for the families of children with innate variations of sex characteristics
- Provide redress to persons with innate variations of sex characteristics having undergone such medical procedures

## 4 Intersex people

IHRA defines intersex people in line with a 2016 statement by human rights experts, published by the OHCHR:

*Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies (Office of the High Commissioner for Human Rights 2019)*

We acknowledge the diversity of intersex people in our diagnoses, identities, legal sexes assigned at birth, genders, gender identities, and the words we use to describe our bodies. At least 40 different intersex variations are known (Hiort 2013), most of which are genetically determined.

Respondents to a large Australian sociological study of people born with atypical sex characteristics in 2015 (T. Jones et al. 2016) had more than 35 different variations, including 5-alpha-reductase deficiency, complete and partial androgen insensitivity syndrome (AIS), bladder exstrophy, clitoromegaly, congenital adrenal hyperplasia (CAH), cryptorchidism, De la Chapelle (XX Male) syndrome, epispadias, Fraser syndrome, gonadal dysgenesis, hyperandrogenism, hypospadias, Kallmann syndrome, Klinefelter syndrome/XXY, leydig cell hypoplasia, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH, mullerian agenesis, vaginal agenesis), micropenis, mosaicism involving sex chromosomes, mullerian (duct) aplasia, ovo-testes, progestin induced virilisation, Swyer syndrome, Turner's syndrome/X0 (TS), Triple-X syndrome (XXX).

Clinicians frequently use a stigmatising label, 'Disorders of Sex Development' ('DSD'), to refer to intersex variations.

In legislative settings, we propose use of terminology such as 'innate variations of sex characteristics' to refer to people with relevant traits, in order to facilitate legislative and regulatory protections irrespective of diagnosis, age, agency, legal classification, or identity.

## 5 Relevant treaty body recommendations to Australia

In response to submissions by IHRA and others, the Human Rights Committee (2017), Committee on Economic, Social and Cultural Rights (2017), Committee on the Elimination of Discrimination against Women (2018), Committee on the Rights of the Child (2019) and the Committee on the Rights of Persons with Disabilities (2019) have called on the Australian government to ensure that children with intersex variations are protected from human rights abuses in medical settings, and called for access to peer support, and redress.

The Committee on the Elimination of Discrimination against Women and the Committee on the Rights of the Child have made recommendations that positioned forced and coercive medical interventions on intersex children within its framework on harmful practices. Sustainable Development Goal target 5.3 refers to the elimination of harmful practices (Sustainable Development Solutions Network Undated).

In July 2018, in concluding observations to Australia, the Committee on the Elimination of Discrimination against Women (CEDAW), made the following statements:

### ***Harmful practices***

*25. The Committee takes note of the State party's commitment to providing support for women who are victims of forced marriage, regardless of their cooperation with the prosecution authorities. It is concerned, however, about the following:*

*[...] (c) The conduct of medically unnecessary procedures on intersex infants and children before they reach an age when they are able to provide their free, prior and informed consent, as well as inadequate support and counselling for families of intersex children and inadequate remedies for victims; [...]*

*26. Recalling the joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices, the Committee recommends that the State party ensure adequate protection and support for victims of forced marriage, regardless of their collaboration with the prosecution authorities, and also recommends that the State party:*

*[...] (c) Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures; (Committee on the Elimination of Discrimination against Women 2018)*

In September 2019, the Committee on the Rights of the Child made similar recommendations to Australia:

### ***Harmful practices***

*31. The Committee welcomes the criminalization of forced marriage and taking note of target 5.3 of the Sustainable Development Goals, urges the State party to:*

*[...] (b) Enact legislation explicitly prohibiting coerced sterilisation or unnecessary medical or surgical treatment, guaranteeing bodily integrity and autonomy to intersex children as well as adequate support and counselling to families of intersex children. (Committee on the Rights of the Child 2019)*

In 2019 the Committee on the Rights of Persons with Disabilities in document CRPD/C/AUS/CO/2-3 positioned their recommendations to Australia within its comments on Article 17, “Protecting the integrity of the person”:

***Protecting the integrity of the person (art. 17)***

*33. The Committee is seriously concerned about:*

*(a) Ongoing practice of forced sterilization, forced abortion and forced contraception of persons with disabilities, particularly women and girls, without their free and informed consent, which remains legal;*

*(b) Unregulated use of involuntary surgery on infants and children born with variations in sex characteristics, and other intrusive and irreversible medical interventions, without their informed consent or evidence of necessity.*

*34. The Committee urges that the State party to:*

*(a) Review and amend the Family Law Rules 2004 relating to Medical Procedure Applications in line with the Convention and adopt uniform legislation prohibiting, in the absence of free and informed consent, the sterilization of adults and children, the administration of contraception and abortion procedures on women and girls with disability;*

*(b) Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary, invasive and irreversible medical interventions, including surgical, hormonal or other medical procedures on intersex children before they reach the legal age of consent ... without their free and informed consent of the person concerned; also provide adequate counselling and support for the families of intersex children and redress to intersex persons having undergone such medical procedures. (Committee on the Rights of Persons with Disabilities 2019)*

In appearances before UN Treaty Bodies, Australian government staff have sadly mistaken intersex for transgender, and have been put in the position of defending early surgeries, or acknowledging that such practices are ‘under review by the Government’ (see, for example, Stop IGM 2017; Attorney General’s Department 2018).

In the sixth periodic report submitted by Australia to the Committee (Australian Government 2019), reference is made to inquiries by the Australian Law Reform Commission (ALRC) and Australian Human Rights Commission (AHRC), which we refer to in following sections. To summarise, the ALRC report made no relevant recommendations. The AHRC report made constructive recommendations in 2021, but the government has not responded to the report.

No actions have been taken by Australian jurisdictions to ensure that infants, children, adolescents and adults are protected from such practices, except for proposals for legislative reform in the Australian Capital Territory and, at a much earlier stage, in Victoria.

There is no substantive resourcing for support for children and families, with the exception of some funding in the Australian Capital Territory and pilot or intermittent funding in Victoria and Queensland.

No provisions have been made to provide redress to individuals subject to interventions without their personal informed consent.

## 6 National inquiries and position statements

Australia is fortunate, and unusual internationally, in having two major national inquiries that have reported on the health and human rights of people with intersex variations:

- a 2013 report by the Senate Community Affairs References Committee on the involuntary or coerced sterilisation of intersex people, and
- a 2021 report by the Australian Human Rights Commission on ensuring the health and human rights of people born with variations of sex characteristics.

While the existence of these inquiries is an expression of the hard work of advocacy by IHRA and others, the recommendations of neither inquiry have been implemented. In 2017, we co-ordinated the drafting of a community declaration setting out our demands. We have also collaborated where practicable with clinical organisations.

### 6.1 Senate committee report, 2013

In 2013, the Senate's Community Affairs References Committee, charged with oversight of healthcare, held an inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people (Senate of Australia Community Affairs References Committee 2013). In its 2013 report, the Senate committee found that:

*there is no medical consensus around the conduct of normalising surgery...*

*Normalising appearance goes hand in hand with the stigmatisation of difference...*

*There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues. Those issues include reducing parental anxiety, and ensuring social awareness and acceptance of diversity such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues (Senate of Australia Community Affairs References Committee 2013)*

The Senate report called for protocols and guidelines consistent with recommendations by IHRA (then named Organisation Intersex International Australia):

*3.129 The proposals put forward by Organisation Intersex International have merit, and are consistent with the committee's conclusions. The committee believes that a protocol covering 'normalising' surgery should be developed, and then adhered to in all cases of intersex children. Such a guideline should be consistent with Organisational Intersex International's recommendations (Senate of Australia Community Affairs References Committee 2013)*

Responding to the Senate inquiry, the federal government stated 'the substantive regulation of medical treatment is a matter for state and territory governments' (Attorney General's Department 2015). However, the federal government has played a key role in establishing a national framework for similar legislation, for example, in ensuring nationally consistent legislation to prohibit female genital mutilation, with a review of such legislation

occurring contemporaneously with the Senate inquiry (Attorney General's Department 2013).

No Australian government has implemented the Senate committee recommendations. Medical practices that take place too early to have regard for individuals' values and preferences have persisted unchanged, including early feminising surgeries, masculinising surgeries, and sterilisations.

## 6.2 Darlington Statement, 2017

The *Darlington Statement* is a community consensus statement by Australian and Aotearoa/New Zealand intersex organisations and advocates, signed in March 2017 (AIS Support Group Australia et al. 2017). The Statement informs our position. In it, we identify our core human rights concerns as including:

*5. Our rights to **bodily integrity, physical autonomy and self determination** (AIS Support Group Australia et al. 2017).*

Key relevant concerns identified in the Statement aim to address stigma, shame, a lack of oversight of medical practices and failure to respect the human rights of children in medical settings:

*B. We observe that, despite the best efforts of intersex human rights defenders, discrimination, stigmatisation and human rights violations, including harmful practices in medical settings, continue to occur in Australia and Aotearoa/New Zealand.*

*16. Current forms of **oversight of medical interventions** affecting people born with variations of sex characteristics have proven to be inadequate.*

*a. We note a lack of transparency about diverse standards of care and practices across Australia and New Zealand for all age groups.*

*b. We note that the Family Court system in Australia has failed to adequately consider the human rights and autonomy of children born with variations of sex characteristics, and the repercussions of medical interventions on individuals and their families. The role of the Family Court is itself unclear. Distinctions between "therapeutic" and "non-therapeutic" interventions have failed our population. (AIS Support Group Australia et al. 2017)*

In the Statement, we call for a set of interrelated reforms:

- *prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children [born with variations of sex characteristics] without personal consent*
- *mandatory independent access to funded counselling and peer support [i.e. resourcing of intersex-led organisations to provide peer support, systemic advocacy and services]*

- *appropriate human rights-based, lifetime, intersex standards of care with full and meaningful participation by intersex community representatives and human rights institutions*
- *independent, effective human rights-based oversight mechanism(s) to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations (AIS Support Group Australia et al. 2017)*

### **6.3 Australian Law Reform Commission report, 2019**

The State party report to the Committee dated 2019 refers to an inquiry of the Australian Law Reform Commission (ALRC) that might make recommendations in relation to family law and the treatment of people with intersex variations. A 2018 discussion paper raised relevant questions (Australian Law Reform Commission 2018), but the final report contained no relevant discussion or recommendations. Recommendations instead focused on a perceived need to re-balance arrangements between the Commonwealth (federal level of government) and States and Territories (Australian Law Reform Commission 2019).

### **6.4 Australian Human Rights Commission report, 2021**

In October 2021, our National Human Rights Institution, the Australian Human Rights Commission (AHRC), made 12 recommendations in a report, *'Ensuring health and bodily integrity'* (2021) aimed at ensuring a human rights-based approach to decision-making on medical interventions. We thank the AHRC for their work. The report builds on recommendations of the earlier Senate committee inquiry.

As anticipated, the report found that some early surgical interventions are necessary for physical health and well-being, or permissible with personal informed consent, but others are justified through appeals to gender stereotypes and medical eminence, fears of future stigmatisation, and overly loose conceptions of medical necessity and therapeutic treatment that permit these as rationales for treatment and consented to by parents or carers (Australian Human Rights Commission 2021, 44 and 74). There is no firm evidence base for current medical practices (Australian Human Rights Commission 2021, 74 and 119; Lee et al. 2016, 176).

Doctors specialising in aspects of physical health have argued that psychosocial factors and mental health are appropriate reasons for early surgical intervention. However, professional bodies of psychiatrists and psychologists have rejected these rationales because of the mental health consequences of treatment without personal consent on such fundamental aspects of people's bodies and identities (Australian Human Rights Commission 2021, 78 and 81).

Additionally, the AHRC report found it necessary to refute a straw man argument, that some advocates want 'a complete moratorium on all genital/gonadal surgery until the individual is able to give informed consent' (these claims are also evident in recent Australian clinical papers, such as Vora et al. 2021; Vora and Srinivasan 2020). Citing a submission by the Australasian Paediatric Endocrine Group, the AHRC commented:

*Some stakeholders seemed to base their opposition to any legal sanctions on the premise that all medical interventions modifying sex characteristics would be prohibited, in all circumstances. However, neither the Commission nor any stakeholders have advocated such a blanket prohibition (Australian Human Rights Commission 2021, 131).*

The 2021 AHRC and 2013 Senate committee reports provide a firm basis for legislative reform, and associated oversight, treatment standards, and resourcing of peer and family support and advocacy. The AHRC state that:

*There is real risk that, without changes to oversight mechanisms, interventions will continue to be made that are not medically necessary and which could have been deferred under a precautionary approach. Current practice has included interventions that are based on psychosocial rationales, such as gender-conforming treatments. [...] current international and Australian clinical guidance allows clinicians to take psychosocial factors, such as cultural or social pressure, into account as relevant when considering whether an intervention should be proposed. (Australian Human Rights Commission 2021, 120)*

The AHRC recommendations address the following matters:

- legislative reform by Australian governments to ensure that medical interventions to ‘modify the sex characteristics of people born with variations in sex characteristics should be guided by a human rights framework’, with effective independent oversight, and with criminal penalties
- resourcing for peer support and advocacy organisations; development of new resources to increase awareness and reduce stigma, developed by community organisations with public funding
- new national guidelines, which are not intended to eliminate a need for framework legislation
- access to comprehensive care across the lifespan
- funding for community-led research and national data.

To date, only one of eight States and Territories (the Australian Capital Territory) has published draft legislation to prohibit harmful practices on children with intersex variations (Chief Minister, Treasury and Economic Development Directorate 2022a). One additional jurisdiction (Victoria) has sought advice on the form and content of possible legislation (Department of Health 2021).

The federal government has made no response to the report. As yet, it has identified no proposals for either national legislation, nor to ensure nationally consistent legislation.

No other States and Territories, nor the federal government have made formal public responses to the AHRC report recommendations. Many States and Territories, and many federal government departments, unfortunately still struggle to understand the population (Carpenter 2022).

## **6.5 Clinical position statements**

### **6.5.1 Australian Medical Association**

The Australian Medical Association (AMA) adopted a position statement in 2021 that states:

*Being LGBTQIA+ is normal, healthy, and representative of the diversity in human sexuality, gender identity, and sex characteristics. The historical pathologisation of LGBTQIA+ people is associated with poorer health outcomes at the individual and population level (Australian Medical Association 2021)*

The AMA calls on medical practitioners to:

*Affirm Yogyakarta Principle 32 that “no-one should be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person” (Australian Medical Association 2021)*

### **6.5.2 Public Health Association of Australia**

In 2021, the Public Health Association of Australia (PHAA) acknowledged that:

*Infants, children, and adolescents with intersex variations remain subjected to unnecessary elective medical interventions in Australia that are understood to be human rights abuses (Public Health Association of Australia 2021)*

The PHAA called on governments to ‘implement appropriate legislative reform’ to ‘end human rights abuses in medical settings’ (Public Health Association of Australia 2021).

### **6.5.3 Royal Australian and New Zealand College of Psychiatrists**

In a 2018 submission to the Australian Human Rights Commission, the Royal Australian and New Zealand College of Psychiatrists stated:

*The RANZCP is a strong advocate for person-centred care and is committed to improving practices that fully respect and incorporate the wishes of the individual. This is no less important for people born with variations in sex characteristics [...]*

*The RANZCP is concerned that sex reassignment decisions may be made within an overly narrow frame. Primum non nocere – do no harm – is central to medical ethics and carries with it powerful and longitudinal meaning for this group. Therefore, the RANZCP supports the deferral of sex assignment treatment decisions which have irreversible consequences until the person can provide informed consent, except in cases of medical necessity. [...]*

*While further legal consideration may be required to determine whether a legal definition of medical necessity of therapeutic treatment would be helpful, the RANZCP is concerned about the use of psychosocial rationales to justify intervention. There is little evidence for sex assignment therapies leading to positive or negative mental health outcomes. Accordingly, claims that sex assignment therapies are ‘necessary’ or ‘therapeutic’ are dubious [...] The RANZCP supports a cautious approach to decision making where there is no physical necessity for intervention (Royal Australian and New Zealand College of Psychiatrists 2018).*

The College further stated in a 2021 position statement on LGBTIQ+ mental health:

*Decisions about the medical and surgical care of intersex babies, children, adolescents, and adults should be informed by perspectives of lived experience, human rights, dignity, family and cultural perspectives, thorough informed consent, and the avoidance of unnecessary interventions. (Royal Australian and New Zealand College of Psychiatrists 2021)*

#### **6.5.4 Australasian Paediatric Endocrine Group**

In a public submission to the 2013 Senate committee inquiry process, the Australasian Paediatric Endocrine Group (APEG), a group of paediatric endocrinologists and scientists, suggested there are clear indications for surgeries:

*Indications for surgery in DSD involve management of high cancer risk in the testes or ovaries, management of dysfunctional urine flow, creation of a vagina, or surgery for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis (Australasian Paediatric Endocrine Group et al. 2013)*

Management of high cancer risks and urinary issues should not be controversial. However, these issues are intertwined with non-therapeutic rationales for treatment. The Senate Committee was itself 'disturbed' by entwinement of different rationales in clinical reports (Senate of Australia Community Affairs References Committee 2013).

Regarding 'Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis', APEG stated:

*The purpose of these procedures is for functional reasons such as to allow a male individual to urinate while standing, and for psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing (Australasian Paediatric Endocrine Group et al. 2013).*

The term 'functional' is used inappropriately here: surgeries to ensure a man can urinate while standing are cultural, not functional, requirements for cosmetic interventions. The use of rationales explained as for psychosocial purposes by this group of non-mental health specialists is in direct opposition to the statements of mental health professionals who are qualified to assess such matters.

Subsequent to such interventions APEG notes a lack of clear evidence regarding outcomes following 'early surgical management for reasons of appearance', with:

*particular concern regarding sexual function and sensation (Australasian Paediatric Endocrine Group et al. 2013)*

This report thus clearly identifies how appearance is prioritised over sexual function and sensation. In a 2022 position statement, APEG recognised the harm of unspecified 'past' practices:

*APEG acknowledges that some past clinical interventions led to harm, and APEG is committed to working with all stakeholders to achieve optimal outcomes in future (Hewitt et al. 2022)*

No further detail is provided about which practices are acknowledged to have led to harm, when they might have ceased, or what alternative practices and procedures are now in place. The Position Statement makes no formal apology or redress, and provides no acknowledgement of the human rights of people in the care of its members.

This position is impossible to verify, and it provides no way of holding the institution or its members to account. However, our documentation of medical practices and attitudes, in the following section, shows:

- a continued commitment to early unnecessary medical interventions, including at the highest levels in clinical care
- disregard for the human rights of children and former patients
- unsubstantiated claims of reform which turn out to be unreliable or false
- no indication of any change in the prevalence of harmful practices.

## 7 Human rights abuses in medical settings

In this section we outline evidence relating to clinical practices that violate the human rights of people with intersex variations, including infants, children and adolescents. We have gathered evidence from multiple jurisdictions, documented in clinical publications and in other publicly available sources, such as a debate between paediatric surgeons and bioethicists including our executive director.

We outline some broad concerns with ‘surgical options’ and other cross-cutting issues such as disregard of the rights of the child. We then outline known concerns with feminising surgeries, masculinising surgeries, and sterilisation.

### 7.1 Clinical perspectives promoting unnecessary surgeries

Here we outline human rights abuses documented in Australian sources that speak to clinical beliefs and treatment paradigms

#### 7.1.1 Sex determination and ‘surgical options’

In cases where sex determination is in doubt, Vora and Srinivasan – paediatric endocrinologists in New South Wales, Australia – stated in a 2020 article in the *Australian Journal of General Practice* that:

*assignment is a dilemma in a small percentage of patients with DSD and requires an individualised approach taking into consideration prenatal androgen exposure, fertility potential, quality of sexual function, surgical options, gonadal pathology/malignancy risk and potential adult gender identity (Vora and Srinivasan 2020, 418).*

Morgan Carpenter wrote to a co-author of this paper in September 2021 in an attempt to ascertain the meaning of ‘quality of sexual function’ and query other matters, but no response has been received.

The reference to ‘quality of sexual function’ and ‘potential adult gender identity’ appear indicate an attempt to predict a more likely future gender identity and sexual role, reflecting an attempt to construct future cisgender, heterosexual adults.

The reference to ‘surgical options’ is a clear indication of the persistence of early unnecessary medical interventions to modify sex characteristics that are predetermined by sex registration. This is illustrated in statements on 17 $\beta$  hydroxysteroid dehydrogenase 3 deficiency (17 $\beta$ -HSD3) in the World Health Organization Foundation for the International Classification of Diseases:

*If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized (World Health Organization 2022)*

In our view, it is perfectly acceptable for a provisional legal and social assignment of sex to occur, with neither surgical nor other medical intervention being required as a result.

This trait is ‘often misdiagnosed in infancy and detected at puberty in genetic males who have been either raised as females and develop hirsutism and primary amenorrhoea, or raised as males and have gynecomastia and incomplete male genital development’ (World

Health Organization 2022). This indicates that risks or experiences of early surgeries and hormonal interventions due to gender stereotypes are not limited to situations where sex determination is considered challenging.

### 7.1.2 'Fixing' children and medical experimentation

In a recorded and publicly-viewable debate between paediatric surgeons and bioethicists in 2020, Professor John Hutson AO described the sexual development of children with intersex traits as 'incomplete' and in need of being 'fixed' (Hutson et al. 2020). Professor Hutson is a recipient of the Order of Australia (one of Australia's highest awards) for his services to medicine, 'particularly in the field of paediatric surgery' and a recipient of the American Academy of Pediatrics medal in Urology (Royal Children's Hospital Melbourne Undated). He is the chair of paediatric surgery at the University of Melbourne. Professors Sonia Grover and Clare Delany, and Morgan Carpenter, also participated. Hutson, Grover and Delany are all associated with the Royal Children's Hospital, Melbourne.

In the debate, Hutson described the bodies of children with intersex traits as 'incomplete' and to 'fix', mirroring the words quoted by Juan E. Méndez in his 2013 report (UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment 2013):

*Professor John Hutson: The secret is that you've got to make sure that they [parents] understand normal sexual development and the child's, the sexual development if this particular baby is incomplete. We haven't figured out yet what the real gender is. And that doesn't mean that we won't be able to and that we won't be able to fix it.*

*And I agree with Sonia, that the most important thing is to make them understand that they've otherwise got a completely normal baby, usually. Once they've got that in perspective, it's not so difficult for them to cope with the fact that the anatomy is not quite right.*

*Professor Sonia Grover: Not quite typical.*

*Morgan Carpenter: Can I just raise a couple of concerns here. I have just heard words about development being incomplete, about not being normal, and about "fix it". And the student's themselves have come up with this language about intersex variation being normal. So what you're saying here is something that is quite at variance with their framing of the discussion.*

*Professor Sonia Grover: So I think...*

*Morgan Carpenter: This language about being incomplete is particularly interesting. There's quite a long history of language about being incomplete or unfinished, which presupposes that clinicians can finish or complete something.*

*Professor Clare Delany: Sonia? Oh, sorry, John?*

*Professor John Hutson: And the truth is sometimes they can do that. But not always.*

Hutson also expressed his view that he does not have regard to the rights of the child:

*Morgan Carpenter: I also want to raise another issue and that's that if we are talking about when we know somebody's gender. I don't think we necessarily know somebody's gender when we assign a sex of rearing. We don't know somebody's gender really until they are ready to express it themselves.*

*Professor John Hutson: Well, I think that from my point of view, I'm not worried about the rights of the child or moral issues when I see a baby. I'm worried about how the parents are reacting to the fact that they have found that the baby isn't what they were expecting. And my job is to try and help them come to terms with that with whatever, you know, tools are available in the medical toolkit to fix them. To help them, if they think that's what required.*

*And most of the time, I'm looking after children with CAH, where they have got genitalia that are not either normally female or normally male, but are looking different. And the parents are very stressed by this because it is not what they were expecting because your average parent has never heard about intersex or DSD and they are expecting it to look obviously like a boy or a girl and my problem is trying to help them come to terms with the fact that it isn't looking the way they were expecting and what are we going to do about it. (Hutson et al. 2020)*

Professor Hutson also talked about medical experimentation, and attributed poor outcomes experienced by many advocates with intersex variations to medical experimentation on subjects unable to personally consent:

*Professor John Hutson: surgery for adrenal hyperplasia has been very controversial for a very long time. And one of the reasons it is very controversial is because when it was first started, nobody knew how to do it and it is really important for the medical students to recognise that adrenal hyperplasia, as a diagnosis, a disease that we understood, the abnormality in the hormones, we have only known about it since 1953. So actually I am older than the oldest person in the world who had CAH diagnosed at birth. Because I'm born from 40s. Okay? So in what that means is that in 1950s and 1960s doctors were learning to have, or learning how to treat what they thought was an important abnormality by medical and surgical treatments. And like all learning is done by trial and error. And so lots of the surgery, lots of the medical treatment, was either not very good or was actually totally wrong because at the time they didn't actually know how to do it. So they had to learn how to do it, and there was no other way to learn than by trial and error.*

*So there is a whole generation of people in the world who have had surgery, often in infancy, and in retrospect it does not look very good or might be completely wrong.*

*But the important thing to recognise is that at the time they had the surgery it, the doctors thought it was the right thing to do. Given the amount of knowledge they had at the time.*

*So one of the difficulties here is that the intersex community of the world are often, are often responding to the fact that they might have had treatment on themselves in infancy or childhood that turned out to be wrong, because we didn't know at the time how to make it better.*

*But every day we are learning how to do it better and better, and we are never doing it for what we think is inappropriate or unethical reasons, we are always trying to do it for the most ethical and the most efficient way, but that does not mean that we are perfect. We are clearly not perfect. But we are trying to, doing it better and better.*

Claims about improved surgical techniques producing better outcomes fail to address the central issues of stigma, and the purpose and necessity of medical intervention. In response, Morgan Carpenter stated:

*There are some ethical principles that are not so contested. Those principles are fundamental human rights principles. And those principles talk about other things. They talk about the rights of the child. They talk about the right to bodily integrity. The right to physical autonomy. And they also talk about the right to freedom from experimentation. Because children, while saving children's lives is a really fundamental imperative of medicine, this narrative about scientific progress and about how surgeries were not right, that is not a process... Children are not your objects to experiment on to get surgery right. When surgery is elective, where surgery is about what is cosmetic, that is not acceptable, that is not a good balance of rights (Hutson et al. 2020).*

These descriptions of people with intersex variations are prejudicial, and indicative of clinical support for harmful practices at the highest levels of medicine. There has been no apology or redress for unnecessary and harmful medical interventions; these persist on infants and children before they have age and agency to express their values and preferences.

### **7.1.3 Low quality research**

Clinical studies are scarce, lack replication, and rely on small samples and case studies that are subject to ascertainment bias and confirmation bias, for example, where staff at a paediatric hospital study their own patients in line with their own beliefs, values and preferences.

Australian evidence supporting current medical practices relies on a small single-centre study of 'long-term psychological, sexual and social outcomes' by clinicians at the Murdoch Children's Research Institute and Royal Children's Hospital of 50 of their patients (Warne et al. 2005). There is no evidence (or community knowledge) of community input into study design. The study appears intended to justify the centre's treatment model, with the clinicians reporting:

*Most patients with intersex had positive psychosocial and psychosexual outcomes, although some problems were reported with sexual activity. These results overall suggest that a model of care including early genital surgery carried out at a centre of excellence with a multidisciplinary team can minimize long-term complication rates (Warne et al. 2005).*

In 2020, this same small study by clinicians studying their own patients according to their own interests and paradigms is still relied upon as a justification for early surgery:

*As all the participants in this follow-up study had genital reconstructive surgery in infancy or early childhood, the results did not support a change in this practice (Hutson 2020).*

Writing in 2020, the clinicians also note significant concerns:

*The DSD patients were less likely to experience orgasm and tended to experience more pain during intercourse, and they also had more difficulties with penetration than the combined control groups. In addition, they were also more likely to have less frequent sexual activity than the control groups (Hutson 2020).*

Respondents 'reported lower self-esteem and higher anxiety traits' than controls, but had a 'generally positive psychosocial and psychosexual outcome which is in contrast to many other studies' (Hutson 2020). The report on this study appealed to surgical expertise at the centre as a factor in explaining outcomes perceived as good and supportive of surgical practices.

However, a systemic review by an independent team at an institute for psychiatry in Hamburg, Germany reported on the same study differently, indicated significant psychological distress in the study population:

*In the study by Warne et al. (2005), the persons with DSD were similarly as distressed as a comparison group of chronic somatically ill persons. Even though the rates of psychological distress are not directly comparable to our measures, the results similarly indicate markedly increased distress in persons with DSD. (For comparison, German prevalence rates of significant psychological distress in chronically somatic ill persons range from 43% to 50%, see Harter, 2000). (Schützmann et al. 2009).*

In relation to the German team's overall findings, the authors comment on the scale of adverse psychological outcomes:

*Our results suggest that adults with DSD are markedly psychologically distressed with rates of suicidal tendencies and self-harming behavior on a level comparable to non-DSD women with a history of physical or sexual abuse (Schützmann et al. 2009).*

Beliefs underpinning medical interventions lack evidence and clear indications. For example, reflecting an earlier 2006 statement, a 2016 global clinical review states:

*There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization (Lee et al. 2016).*

In 2017, the Committee on Bioethics of the Council of Europe reported that no clinically-accepted standard of care:

*has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance (Zillén, Garland, and Slokenberga 2017)*

#### **7.1.4 Responses to Australian Capital Territory draft legislation**

In 2019, the Australian Capital Territory (ACT) government made a commitment to legislate to end harmful practices on people with intersex variations in medical settings. We commend the ACT government for this commitment, and we note that IHRA staff have been contracted work with the ACT government on aspects of resulting work.

In 2022 the ACT government published draft legislation to protect the human rights of people with innate variations of sex characteristics in medical settings. The listening report on submissions includes the following reported statements:

*Intersex and LGBTIQ+ organisations and mental health professional organisations prefer a legislated restriction on medical interventions.*

*Health professionals and their organisations and, some parents rejected the need for the legislation, and challenged the scope of the legislation.*

*Some medical professional stakeholders [had a view] arguing that psychosocial factors or 'social integration' should be valid reasons to undertake medical interventions without personal consent.*

*Some health professionals also argued that their work on children's health is appropriately based on social norms, while other health professionals presented an objection on the opposite grounds: they rejected the argument that intersex healthcare is influenced by social expectations about bodies (Chief Minister, Treasury and Economic Development Directorate 2022b).*

In an indication of the impact of stigma and discriminatory attitudes that are not assuaged by clinical practices, reference was made by one clinician to a possibility of increased prevalence of pregnancy terminations:

*A medical professional commented that the Bill may have unintended consequences on people's decision to terminate pregnancy should a variation in sex characteristics be identified prenatally. (Chief Minister, Treasury and Economic Development Directorate 2022b)*

We understand that the ACT government is continuing to work towards publication of legislation to implement human rights protections for people with innate variations of sex characteristics in medical settings, and we warmly welcome this.

#### **7.2 Feminising surgeries**

These include early genitoplasties, clitoral reductions, vaginoplasties and labioplasties, intended to make genital appearance and function fit gender stereotypes for female bodies. Publicly reimbursable medical procedures include the following paediatric-only codes, unavailable to adults who are able to personally consent to treatment:

- 37845 Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with or without endoscopy
- 37848 Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with endoscopy and vaginoplasty

37851 Congenital disorder of sexual differentiation, vaginoplasty for, with or without endoscopy (Carpenter 2022)

The lack of direct analogues for adults, means that surgeries on children are incentivised.

### **7.2.1 Evidence from Victoria**

In a media report on feminising surgeries in 2013, the Royal Children’s Hospital Melbourne, Victoria, is reported to perform ‘10-15 genital reconstruction operations a year often on girls under the age of two’, described as ‘gender assignment or genital enhancement operations’ (Bock 2013). In the same year, the hospital reported to the Senate an ‘opinion’ favouring early surgeries (Royal Children’s Hospital Melbourne 2013, 7).

The description of early genital surgeries on ‘girls under the age of two’ as ‘genital enhancement operations’ is particularly abhorrent.

There appears to be no clear correlation between these surgery numbers at a single hospital and contemporaneous data on numbers of relevant surgeries appearing in Medicare data, nor a federal Department of Health review of vulvoplasties that refers to ‘congenital malformations’ associated with intersex-specific ICD codes (Carpenter 2018b, 468–74).

Safer Care Victoria, an agency of the State government charged with healthcare safety and improvement, omits consideration of human rights concerns and is inappropriately suggestive of a variety of acceptable perspectives, in a statement that normalises early elective surgeries in relation to infants with congenital adrenal hyperplasia, and gives them governmental approval:

*Most surgical correction [sic] is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options (Safer Care Victoria 2021)*

All surgeries that are not necessary for physical health and wellbeing – including so-called ‘surgical correction’ – should be delayed until individuals are old enough to freely express their values and preferences.

### **7.2.2 Evidence from Queensland**

In 2012 the Queensland government had asserted:

*Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention, to determine the sex of the child early in their life. Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health (Department of Communities 2012)*

This assertion makes all the more remarkable and profoundly disturbing comments by a Family Court judge in a case adjudicated in 2016. The case, *Re Carla (Medical procedure)*, adjudicated in Brisbane, may have been instrumental in instigating an inquiry on protecting the human rights of people born with variations of sex characteristics in medical settings by the AHRC. It involved a pre-school child with 17 $\beta$  hydroxysteroid dehydrogenase 3 deficiency, described by the judge as a ‘sexual development disorder’. The judge stated that the child had already had surgeries that ‘enhanced the appearance of her female genitalia’, without recourse to the court but indicating a prior investment in a particular future

appearance and identity (Family Court of Australia 2016, para. 2; Carpenter 2018a; Australian Human Rights Commission 2021). This statement regarding the purpose of cosmetic surgeries is abhorrent, and makes previous State government assertions regarding irreversible procedures profoundly troubling.

The case was taken to remove the child's gonads, and the judge determined that parents could authorise this treatment (Family Court of Australia 2016, para. 19; Carpenter 2018a; Australian Human Rights Commission 2021).

In 2019, a clinical team in Brisbane published a 'review of adolescent females ages 8 to 18 years of age with DSDs' managed by the Paediatric and Adolescent Gynaecology Service 'over the last 10 years' (Adikari et al. 2019). This period overlaps with both the Senate inquiry of 2013 and the AHRC inquiry that commenced in 2018. The review states that:

*The most common reasons for referral were primary amenorrhea, hormone replacement, and vaginal dilation and the average age initial review 17 years, 3 months. 5 adolescents were unaware of their diagnosis prior to referral and assessment, with 13 diagnosed in infancy with ambiguous genitalia [sic] or hernia (Adikari et al. 2019).*

In relation to all five instances reporting regarding children with partial androgen insensitivity, the paper stated:

*'Gonadectomy and feminizing genitoplasty 1 year age.'*

*'Gonadectomy and reconstructive surgery as infant.'*

*'Gonadectomy and surgical creation neovagina as child.'*

*'Gonadectomy and feminizing surgery age 2yo.'*

*'Bilateral gonadectomy.'* (Adikari et al. 2019).

Feminising genital surgeries were also reported in cases involving an adolescent with 5-alpha reductase deficiency and an infant with mixed gonadal dysgenesis. No information was disclosed in relation to treatment of children with congenital adrenal hyperplasia seen at this clinic, but we anticipate that feminising genital surgeries were routine.

In cases where genitoplasties occurred during later childhood or adolescence, it is plausible that diagnosis and referral occurred later.

These procedures also can be contrasted with a previous statement by the Queensland government that asserted they do not occur (Department of Communities 2012).

### **7.3 Masculinising surgeries**

Boys who may not be able to urinate standing up may undergo multiple surgeries to ensure they are able to urinate 'appropriately' (McLennan 2021). This presentation of 'appropriateness' of urination standing up indicates that treatment is being framed as 'functional', rather than 'cosmetic' or 'cultural'. It is not functional. It is a cultural norm and a gender stereotype. Related surgeries include 'hypospadias repair', while related interventions include 'erection tests' on pre-pubertal children. Most interventions appear to take place on children. Relevant reimbursable procedures include:

- 37815 Hypospadias, examination under anaesthesia with erection test
- 37816 Hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age
- 37822 Hypospadias, distal, 1 stage repair, on a person under 10 years of age
- 37824 Hypospadias, proximal, 1 stage repair
- 37825 Hypospadias, proximal, 1 stage repair, on a person under 10 years of age
- 37827 Hypospadias, staged repair, first stage
- 37828 Hypospadias, staged repair, first stage, on a person, 10 years of age or over
- 37830 Hypospadias, staged repair, second stage
- 37831 Hypospadias, staged repair, second stage, on a person under 10 years of age.
- 37833 Hypospadias, repair of urethral fistula
- 37834 Hypospadias, repair of urethral fistula, on a person under 10 years of age (Carpenter 2022).

High numbers of masculinising surgeries take place each year in Australia, including hundreds of second or repeat surgeries and, in a sample year, more than a hundred ‘erection tests’ on children younger than 10 years of age (Carpenter 2022).

In a 2020 book, John Hutson and other clinicians at Royal Children’s Hospital Melbourne reported on outcomes of their early masculinising surgeries at that hospital. Hutson asserts improved psychological well-being in boys after early surgery as the primary rationale for early surgical intervention – ‘no serious psychological disturbance and no memory of the intervention’ (Hutson 2020, 311) – accompanied by a claim of surgical expertise (Hutson 2020). The evidence supporting these assertions was a survey of 55 minors aged 13-15 with a low response rate (B. Jones et al. 2009). The study population was too young to be able to ascertain outcomes. Lacking memory of a procedure is not an appropriate rationale for early treatment, and it pre-empts the right of any person to exercise personal autonomy regarding medical treatment.

When hypospadias repair procedures go wrong, which is known in a significant proportion of cases, the outcomes can be catastrophic. Articles in the *Journal of Pediatric Urology*, official journal of the Asia Pacific Association of Paediatric Urologists, still refer to children in situations of such iatrogenic harm as ‘hypospadias cripples’ (Neheman et al. 2020).

Clinical papers have identified that long-term outcomes of hypospadias repairs include urethral strictures (a narrowing of the urethra) which may not be evident until adulthood. In relation to these surgeries, Katrina Roen notes ‘questionable decision-making and consent processes (Roen & Hegarty, 2018) and surgical outcomes that urologists themselves find questionable (Long & Canning, 2016; Long et al., 2017)’ (Roen 2019). Non-surgical pathways are lacking (Liao, Wood, and Creighton 2015; Roen 2019).

#### **7.4 Sterilisation**

Any individual subject to sterilising surgeries requires a lifetime of medical treatment to ensure physical and psychological health, such as access to hormone replacement therapies. These are associated with regular examinations, testing and costs.

#### 7.4.1 People with androgen resistance

Persons with androgen resistance, or androgen insensitivity syndrome ('AIS') have XY sex chromosomes (typically associated with men), testes (typically intra-abdominal), and a phenotype or physical appearance that may vary. The majority of people with complete AIS appear to be cisgender women and a high proportion are heterosexual (Warren 2017). People with partial AIS grow up to understand themselves in diverse ways, including many women and girls with a largely typical female phenotype, and people who look and understand themselves in different ways.

Diagnosis may take place at any point during infancy or childhood (for example, if testes are mistaken for herniation) or during puberty (due to lack of menstruation). The nature of androgen insensitivity means that women with complete androgen insensitivity ('CAIS') will never 'virilise' ('masculinise') if their gonads are retained or if they take testosterone replacement therapy. Women and girls with partial androgen insensitivity ('PAIS') may experience some virilisation if their gonads are retained or if they take testosterone replacement therapy depending on the degree of insensitivity to androgens. Men and non-binary people with partial androgen insensitivity may seek virilisation to the extent this is possible. People with 'higher grades' of partial androgen insensitivity have limited capability for virilisation.

Once diagnosed, people with androgen insensitivity are frequently subjected to gonadectomies, or sterilisation. Historically, rates of potential gonadal tumour risk have been overstated. Discussion by a Senate Community Affairs References committee inquiry on involuntary or coerced sterilisation in 2013 found that:

- *The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.*
- *The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions. (Senate of Australia Community Affairs References Committee 2013)*

At the time of the Senate inquiry, clinical reports suggested a 50% gonadal cancer risk associated with some forms of androgen insensitivity, and the Australasian Paediatric Endocrine Group expressed concern about the questioning of low quality data and clinical reporting that emphasised the highest risks:

*Some authors have misunderstood the difference between high-risk and low-risk cancer groups within DSD, and in particular, one submission incorrectly implied that the cancer risk for a diagnosis in the highest-risk group ("PAIS with non-scrotal/intra-abdominal testes") was quoted by Warne and Hewitt as being the cancer risk for a diagnosis in the low-risk group ("CAIS")... The implication is that testes or ovaries are being removed from patients with diagnoses at low-risk of cancer, such as CAIS, however this is incorrect (Australasian Paediatric Endocrine Group et al. 2013).*

Our submission had remarked with concern on the following statements that both emphasised the highest level of risk, and associated that risk with a Y chromosome and intra-abdominal testes. These are characteristic of both people with PAIS and CAIS:

*In any DSD [‘Disorder of Sex Development’] associated with a Y chromosome, there is an increased risk of germ cell cancer, especially when the testes are intra-abdominal (the risk of seminoma in partial androgen insensitivity is 50% for an intra-abdominal testis) or when there is gonadal dysgenesis. (Warne and Hewitt 2009, 612; cited in Carpenter and Organisation Intersex International Australia 2013)*

Current papers suggest a low gonadal tumour risk of 0.8% associated with the gonads of people with complete androgen insensitivity (Pleskacova et al. 2010). A 2021 paper by Victorian clinicians identifies significantly reduced risk levels associated with partial androgen insensitivity:

*Malignancy risk for intra-abdominal gonads in PAIS was previously estimated at ~50%, hence prophylactic gonadectomy to mitigate this risk was recommended. More recently, data from cohorts with genetic confirmation of underlying diagnosis indicate that while the risk remains at ~30%+ for those with gonadal dysgenesis and intra-abdominal gonads, it is now estimated to be considerably lower in PAIS than previously attributed (~7% across studies where causative androgen receptor variant was genetically confirmed). (O’Connell et al. 2021, 7)*

Risk levels of ~7% are comparable to or lower than risk levels associated with breast cancer in women (Queensland Health 2019).

Following sterilisation, individuals require hormone replacement to maintain bone health, libido and general health.

Women with complete androgen insensitivity report assumptions behind medical intervention that include the idea that women should not have testes. These include assumptions that women with complete androgen insensitivity need oestrogen as post-sterilisation hormone replacement, even though their bodies naturally produced testosterone. People with partial androgen insensitivity continue to typically experience surgeries and other treatments that fail to respect their values and preferences.

We are aware of clinical claims that prophylactic sterilisations and genital surgeries on women with androgen insensitivity no longer take place, including claims that such interventions are ‘in the past’. For example, in 2013 the Australasian Paediatric Endocrine Group commented vaguely on a ‘trend towards consideration of less’ surgery, which provides no evidence of an actual shift in practice:

*a trend toward consideration of less genital and gonadal surgery in infants assigned female, or delaying surgery. It is important to note that current practice has changed significantly from the past’ (Australasian Paediatric Endocrine Group et al. 2013).*

We are unable to pinpoint any moment in time that divides that past from the present, and we are unaware of any Australian women with androgen insensitivity aged under 50 who have not been sterilised. In 2019, a clinical team in Brisbane published a ‘review of adolescent females ages 8 to 18 years of age with DSDs’ managed by the Paediatric and

Adolescent Gynaecology Service ‘over the last 10 years’ (Adikari et al. 2019). This period overlaps with the Senate inquiry in 2013 and the AHRC inquiry.

Despite assertions to the contrary made to the 2013 Senate inquiry, all children and adolescents with androgen insensitivity reviewed were subjected to gonadectomies, typically in infancy. The authors report that:

*Gonadectomy was performed in all cases, except in the Turner’s variant. In [children with complete androgen insensitivity], bilateral gonadectomies were most often done at infancy (Adikari et al. 2019).*

All five persons with partial androgen insensitivity were subjected to gonadectomies; in four cases, this was stated to have taken place in infancy or as a child, and associated with feminising surgeries (Adikari et al. 2019).

It was only very recently, in 2019, that a team of clinicians in the United States published a first management protocol for preservation of gonads in individuals with androgen insensitivity (Weidler et al. 2019). We have no data on whether such protocols are being taken up in Western Australia.

We are aware of cases where people with AIS have been unaware of their diagnosis, and so unable to manage key aspects of their life, including the consequences of sterilisation (for example, Kirkland 2017).

#### **7.4.2 People with androgen metabolisation traits**

Infants with 17-beta hydroxysteroid dehydrogenase 3 (17 $\beta$ -HSD3) and 5-alpha reductase deficiency 2 (5 $\alpha$ -RD2) have XY chromosomes and may have genitals that appear at birth to be somewhere between typically female and typically male. In cases where visible genital variation is evident at birth, the currently proposed World Health Organization Foundation for the International Classification of Diseases 11 suggests that gender assignment be made based on a doctor’s subjective assessment of the technical results of masculinising genital surgeries, and that genital surgeries must occur early. Elimination via selective embryo implantation during IVF is also stated as possible. The following statement is from the description for 17 $\beta$ -HSD3:

*If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized (Carpenter 2018a; World Health Organization 2022).*

The Australasian Paediatric Endocrine Group (APEG) acknowledges such interventions, even while advising the Senate in 2013 that such early interventions are controversial and known to be associated with ‘particular concern’ regarding post-surgical sexual function and sensation (Australasian Paediatric Endocrine Group et al. 2013).

Additionally, according to a review paper, rates of gender change in persons with 17-beta-hydroxysteroid dehydrogenase 3 deficiency assigned female at birth are ‘39–64% of cases’ (Cohen-Kettenis 2005). This means that children subjected to feminising genitoplasties may not later come to understand themselves as girls or women.

In 2006, a clinical ‘consensus statement’ described the risk of gonadal tumours associated with 17 $\beta$ -HSD3 to be 28%, a ‘medium’ risk, recommending that clinicians ‘monitor’ gonads (Hughes et al. 2006). A more recent clinical review published in 2010 reduced risk levels to 17% (Pleskacova et al. 2010) and a German multidisciplinary team advised Amnesty International in 2017 that, in any case, ‘cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers’ (Amnesty International 2017).

However, like the WHO ICD-11 classification (World Health Organization 2022), current medical journal articles on this trait (for example, Lee et al. 2016) recommend gonadectomy with female gender assignment, and not on the basis of cancer risks.

In 2008, in the Family Court case *Re Lesley (Special Medical Procedure)*, a judge approved the sterilisation of a young child with 17 $\beta$ -HSD3 (Family Court of Australia 2009). This was intended to prevent the child’s body from virilising at puberty. According to a submission by counsel, the alternative to sterilisation included (at [39]) to:

*(a) take no action and allow [Lesley] to virilise and make a determination about her gender later*

That is, sterilisation was not predicated on clinical urgency regarding cancer risk, but instead to surgically reinforce a female gender assignment and pre-empt later determination. Risks of gonadal tumour were wrongly stated to be ‘significant’ (at [40]).

In 2016, a Brisbane-based Family Court judge adjudicated the case *Re: Carla (Medical procedure)*. An anonymous government department appeared as a friend of the court. The judge concluded that parents could authorise the sterilisation of a pre-school (5-year old) child with 17 $\beta$ -HSD3, surprisingly claiming that ‘it would be virtually impossible to regularly monitor them for the presence of tumours’ (at [20]) (Family Court of Australia 2016). This does not accord with the German experience, or material in a 2006 clinical ‘consensus statement’ that calls on clinicians to ‘monitor’ gonads of people with this trait (Hughes et al. 2006). The judge drew upon affidavits from the child’s multidisciplinary team to describe how (at [30]):

*It will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure*

This indicates a lack of urgency related to tumour potential, in addition to a deliberate constraint on the capacity of ‘Carla’. Gender stereotyping appears to form the substantive basis of the decision to sterilise ‘Carla’, including an assumption of a future female gender identity (at [15]):

- a. Her parents were able to describe a clear, consistent development of a female gender identity;*
- b. Her parents supplied photos and other evidence that demonstrated that Carla identifies as a female;*
- c. She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink*

*curtains, a Barbie bedspread and campervan, necklaces, lip gloss and 'fairy stations';*

- d. She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and*
- e. Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys.*

The judge also expressed, at [18], an assumption of future heterosexuality: 'Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse'.

These interventions pre-empt the right of people make their own decisions, in their own time, in line with their own values and preferences. They exhibit a disregard for the rights of the child and comprise a form of abuse and ill-treatment that occurs with the imprimatur of governmental institutions, and often with public funding.

### **7.5 Adverse outcomes from early general anaesthetic**

Large scale population studies in Australia have confirmed that exposure to general anaesthetic early in life can have adverse consequences for child development. Schneuer and others report:

*Children exposed to general anesthesia before 4 years have poorer development at school entry and school performance. While the association among children with 1 hospitalization with 1 general anesthesia and no other hospitalization was attenuated, poor numeracy outcome remained (Schneuer et al. 2018).*

Children with intersex traits are unnecessarily exposed to these risks because of the role of social stigma and gender stereotypes in justifying early surgical interventions. In some cases, particularly masculinising surgeries, multiple surgeries might occur in a child aged under 4, but these risks are also evident in children subjected to feminising surgeries and sterilisation.

## 8 Legislative provisions facilitating human rights abuses in medical settings

In this section we raise concerns with legislation in multiple Australian jurisdictions that facilitates human rights abuses on children with intersex variations.

### 8.1 Family law and the common law definition of ‘therapeutic treatment’

The *Family Law Act 1975* (Cth) section 67ZC confers statutory authority on the Family Court (now merged into the Federal Circuit and Family Court of Australia) to make orders relating to the welfare of children and directs that in making such orders “a court must regard the best interests of the child as the paramount consideration” (Commonwealth of Australia 2018)

The legal case *Re: Marion* established a common law principle that, to be simplistic, parents can consent to most medical interventions on their children, with the exception of those deemed non-therapeutic.<sup>1</sup> The term therapeutic is not well defined and can have been determined to include ‘cosmetic deformity’. In the case *Re: Carla*, Forrest J (the judge) cited the opinion of Brennan J in *Re: Marion* at [269], where Brennan J stated:

*I would define treatment (including surgery) as therapeutic when it is administered for the chief purpose of preventing, removing or ameliorating a cosmetic deformity, a pathological condition or a psychiatric disorder, provided the treatment is appropriate for and proportionate to the purpose for which it is administered. “Non-therapeutic” medical treatment is descriptive of treatment which is inappropriate or disproportionate having regard to the cosmetic deformity, pathological condition or psychiatric disorder for which the treatment is administered and of treatment which is administered chiefly for other purposes [45] (Family Court of Australia 2016)*

Forrest J heard that all medical witnesses found Carla’s sterilisation to be in her best interests, and argued that this was within ‘the bounds of permissible parental authority’ (Carpenter 2017).

This interpretation of ‘therapeutic treatment’ and the best interests test have not served people with intersex variations. In particular, the best interests test has been utilised to justify early and unnecessary medical interventions. In relation to *Re: Carla*, Kelly and Smith report:

*Forrest J relied on the affidavit evidence of Carla’s parents and her treating medical professionals to conclude that surgery was in Carla’s best interests. In their affidavit, Carla’s parents’ stated that ‘Carla acts as a girl’ and does not identify as ‘anything but female’. [...]*

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<sup>1</sup> The factors which the Court considered significant in determining which cases fall outside the scope of parental authority in *Marion’s Case* were that the procedure was non-therapeutic; invasive and irreversible; that there was a significant risk of making the wrong decision; and that the consequences of a wrong decision would be grave and serious. (*Re: Marion* [250]). While subsequent cases on the scope of the special medical jurisdiction has been debated within cases such as *Re Jamie* and *Re Kelvin*, it is clear that therapeutic status of a procedure remains a key criterion, if not necessarily conclusive of the issue.

*Based on the evidence provided to him, Forrest J approved the gonadectomy, finding it to be in Carla's best interests. Forrest J also approved 'such further or other necessary and consequential procedures to give effect to the treatment of Carla'. Beyond oestrogen treatment these 'consequential procedures' are not defined and for this reason, we are of the view that it was not actually possible to determine that a range of undefined procedures planned for some time in the future, are in Carla's best interests (Kelly and Smith 2017).*

Kelly and Smith argue that the treatment in Re: Carla "sets a dangerous precedent":

*the medical evidence provided to the Court to justify surgery was incomplete and the reasoning and analysis concerning the therapeutic nature of the proposed surgery lacks rigour. In addition, a concerning aspect of Carla's earlier medical care (undertaken prior to the application to the Family Court that was made by Carla's parents in this case), was that the surgical interventions that occurred — which were described as purely cosmetic in nature — were made by the parents and health care team without Court approval. This runs contrary to the principles in Marion's Case (Kelly and Smith 2017).*

Kerridge, Lowe and Stewart state that:

*the therapeutic/non-therapeutic distinction has completely broken down ... The distinction fails to tell us why some treatments need court approval and others do not... The better approach would be to jettison the distinction altogether and to work from an established list of treatments that require approval (Kerridge, Lowe, and Stewart 2013).*

Aileen Kennedy (now a director of IHRA) describes the situation as one of 'complicity between the medical and the legal construction of variations of sex development as pathological disorders in urgent need of correction' where a 'tension between the medical and judicial responses to variations of sex development has disappeared' (Kennedy 2016).

## **8.2 Exemptions in legislation prohibiting female genital mutilation**

Female Genital Mutilation (FGM) refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for 'non-medical reasons' (World Health Organization et al. 2008). In societies where female genital mutilation is a norm, it is recognised to be carried out to, *inter alia*, enable a woman to fully participate in society, prepare for adulthood, and meet cultural standards for female appearance.

Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation (FGM). Implementations of this prohibition facilitate unnecessary medical interventions on girls with atypical sex characteristics.

## **8.3 Australian Capital Territory**

In 1997, the Crimes (Amendment) Act (No. 3) amended the Crimes Act 1900 to prohibit female genital mutilation, with no exemptions in relation to 'cultural, religious or other social custom' but an exemption for 'sexual reassignment procedures' meaning 'a surgical procedure performed by a medical practitioner to give a female person, or a person whose sex is ambivalent, the genital appearance of a person of the opposite sex or of a particular

sex (whether male or female)' (Australian Capital Territory 2018). This facilitates surgical interventions on girls with intersex traits that are prohibited on other girls.

#### **8.4 New South Wales**

In 1995, the Crimes Act 1900 was amended by the Crimes (Female Genital Mutilation) Amendment Act 1994. The provisions contain an exemption for medical procedures including 'sexual reassignment' constructed narrowly to mean surgeries to alter genital appearance 'to the appearance (as nearly as practicable) of the opposite sex to the sex of the person' (New South Wales 1994).

#### **8.5 Northern Territory**

In 1995, the Criminal Code Amendment Act (No. 2) amended the Criminal Code to prohibit female genital mutilation, with no exemptions in relation to 'cultural, religious or other social custom' but an exemption for 'gender reassignment' procedures meaning 'surgical procedure[s] to give a female, or a person whose sex is ambivalent, the genital appearance of a particular sex (whether male or female)' (Northern Territory 1983). This constructs an exemption permitting harmful practices on children with intersex variations.

Information available to us suggests that children in Northern Territory may be referred to Melbourne, Victoria, for surgery.

#### **8.6 Queensland**

In 2000, the Criminal Law Amendment Act prohibited female genital mutilation, with the exception of 'sexual reassignment' procedures defined as 'surgical procedure[s] to give a person the genital appearance of a particular sex, whether male or female' (Queensland 2019), constructing an exemption permitting harmful medical practices on children with intersex variations.

In 2008, the Health Legislation (Restriction on Use of Cosmetic Surgery for Children and Another Measure) Amendment Act prohibited some cosmetic interventions on children, but not procedures on the genitalia of infants and children with intersex variations.

As we identify earlier in this submission, feminising surgeries including procedures that 'enhanced the appearance of [a preschool child's] female genitalia' appear routine in Queensland, despite earlier assurances that irreversible procedures no longer occur (Department of Communities 2012; Carpenter 2018a; Adikari et al. 2019).

#### **8.7 South Australia**

In 1995, the Statutes Amendment (Female Genital Mutilation and Child Protection) Act prohibited female genital mutilation; it contains a narrow exemption for 'sexual reassignment procedures' including surgical procedures 'to give a female, or a person whose sex is ambivalent, genital characteristics, or ostensible genital characteristics, of a male', and an exemption for 'therapeutic' purposes 'directed at curing or alleviating a physiological disability or physical abnormality'.

In February 2022 the Minister for Health and Wellbeing wrote to Morgan Carpenter indicating support for current medical practices (Wade 2022).

## 8.8 Tasmania

In 1999, the Criminal Code Act 1924 is amended by commencement of the Criminal Code Amendment Act 1995, prohibiting female genital mutilation that prohibit procedures for cultural, religious or social customs, but that exempt 'sexual reassignment procedures' including 'a surgical procedure to give a female, or a person whose sex is ambivalent, the genital appearance of a particular sex' (Tasmania 2017).

In a letter to Morgan Carpenter dated 1 December 2021, the Minister for Health stated: 'I am advised that no surgeries to modify the sex characteristics of children are performed in Tasmania' (Rockliff 2021).

The president of the Australian Medical Association in Tasmania referred in the same year to surgeries on boys with atypical sex characteristics being necessary to ensure 'appropriate' urination (i.e. urination standing up) (McLennan 2021). Information available to us suggests that Tasmania exports a proportion of children to Melbourne for surgery.

## 8.9 Victoria

In 1996, the Crimes (Female Genital Mutilation) Act prohibited female genital mutilation with an exemption for 'sexual reassignment' procedures performed by medical practitioners. This appears to provide an exemption in relation to early surgical interventions on children with intersex variations.

In 2008, the Assisted Reproductive Technologies Act prohibited sex selection including reference to 'the purpose of a purpose of producing or attempted to produce a child of a particular sex', which an uninformed reader might take to mean a reference to include intersex people. However, the provisions exempt procedures that 'avoid the risk of transmission of a genetic abnormality or a genetic disease', and this provides a framework for the elimination of embryos with intersex variations.

Evidence available to us shows that so-called "corrective surgeries" persist in Victoria, and a key proponent of such practices has received one of Australia's highest awards for his services to paediatric surgery.

## 8.10 Western Australia

The Gender Reassignment Act 2000 defines 'gender characteristics' and 'reassignment procedures' in relation to children (as well as adults) as follows:

***gender characteristics** means the physical characteristics by virtue of which a person is identified as male or female;*

***reassignment procedure** means a medical or surgical procedure (or a combination of such procedures) to alter the genitals and other gender characteristics of a person, identified by a birth certificate as male or female, so that the person will be identified as a person of the opposite sex and includes, in relation to a child, any such procedure (or combination of procedures) to correct or eliminate ambiguities in the child's gender characteristics; (Western Australia 2000)*

Section 22 of the Criminal Code Amendment Act 2004 introduced a criminal prohibition of female genital mutilation, and explicitly excluded 'a reassignment procedure within the meaning of the Gender Reassignment Act 2000' from the scope of the prohibition (Western

Australia 2004). These provisions are notable for facilitating surgical interventions on children where their sex characteristics ('gender characteristics') differ from gender stereotypes and other normative ideas for female or male bodies.

In a letter in May 2019 to our executive director Morgan Carpenter from Roger Cook MLA, in his capacity as Deputy Premier and Minister for Health, the Minister stated that:

*Children with variations of sex development are offered individualised medical management and care in the public system at Perth Children's Hospital (PCH), including surgical care if required, as children with any other complex medical condition or variance would. [...]*

*Surgery may be indicated for children with variations of sex development for different medical reasons, ranging from reconstructive surgery for variances in development of genitalia, to surgery to minimise high cancer risk in the gonads. (Cook 2019)*

It seems to us that parents of children with intersex variations are offered such treatment, as medical interventions on children with intersex variations frequently take place in children's hospitals before individuals are able to personally consent. Indeed, the Family Court case *Re: Carla (Medical procedures)* demonstrates that many such procedures deliberately take place before children are able to understand such procedures (Family Court of Australia 2016; Kelly and Smith 2017; Carpenter 2018b; Office of the High Commissioner for Human Rights 2019). The statement about 'reconstructive surgery for variances in development of genitalia' is of grave concern to us. Such interventions have been explicitly condemned in statements to Australia on eliminating harmful practices (Committee on the Rights of the Child 2019; Committee on the Elimination of Discrimination against Women 2018).

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